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ABSTRACT

Educators need to understand the grieving process that parents often experience when they learn their child has a handicapping condition. The diagnosis of a handicapping condition may result in a symbolic death--the death of the preconceived "perfect" child, and the death of the parents' plans, hopes, and dreams for that child. The stages of grief as identified by Elisabeth Kubler-Ross can provide structure for addressing the emotional experiences of many parents as they come to terms with having a child who is handicapped. The stages are: denial, anger, bargaining, depression, and acceptance. These stages, as well as initial feelings of shock and the continual need for adjustment, need to be understood by professionals who work with parents of children identified as having handicapping conditions. (DB)

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The Process of Grief as Experienced by Parents of Children with Handicaps

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Abstract

When parents learn that their child has a handicapping condition, their reactions are often similar to persons who have experienced the physical death of a loved one. The diagnosis of a handicapping condition may result in a symbolic death—the death of the preconceived "perfect" child--the death of the parents' plans, hopes and dreams for that child. The stages of grief as identified by Elisabeth Kubler-Ross (1969) provide the structure for addressing the emotional experiences of many parents as they come to terms with having a child who is handicapped. The stages are Denial, Anger, Bargaining, Depression, and Acceptance. These stages as well as initial feelings of shock and the continual need for adjustment are explored. Professionals who work with parents of children identified as having handicapping conditions must be aware of the emotional implications of this grieving process in order to better support parents in their journey toward acceptance.

THE PROCESS OF GRIEF AS EXPERIENCED BY PARENTS OF CHILDREN WITH HANDICAPS

With the enactment of PL 94-142, and more recently the Education of the Handicapped Act Amendments of 1986, our responsibility to serve special children has increased. By 1990 schools will be responsible for providing services to all handicapped children from early infancy.

Although the scope of responsibility is expanding, materials and methods are becoming more sophisticated, and assessment tools and teaching guides are increasing in numbers, one area remains constant: parental reaction to the identification of a child with a handicapping condition. As administrators, classroom teachers, or auxiliary personnel it is important that we be aware of the process of grief as experienced by these parents so that we can be supportive in assisting them as they realize their unique roles.

Elisabeth Kubler-Ross (1969) identified five stages of the grieving process associated with death and dying. These stages are those through which a person will typically pass following the loss of a loved one, as well as by those who are terminally ill and are therefore facing eminent death. The five stages of the grieving process as suggested by Kubler-Ross are (1) Denial, (2) Anger, (3) Bargaining, (4) Depression, and (5) Acceptance (Adjustment). These same stages can be applied with regard to

the process of grief as experienced by parents of children identified as having handicapping conditions.

The first emotional reaction comes with the awareness that the child is not normal. It is a time of shock, a period of complete disbelief, and pure emotion. At this time parents may feel that their entire world has just collapsed. They may feel that they are totally alone.

Long before the birth, parents idealize their child. They envision the perfect child. At the first hint that their child may not fit their predetermined mold, they must begin to gradually forget their cherished plans and, upon a qualified diagnosis, all plans for the child are brought to an abrupt end. This diagnosis may occur at birth, shortly thereafter, or following a period of years after a child is born.

Once the diagnosis is made, parents enter into the first stage of grief, Denial. Denial is a defense mechanism for the stress situation. It is automatic and unconscious and functions as a buffer after the unexpected shocking news.

"This can't be true." It is during this time when parents may actively seek other medical opinions. In so doing, it is hoped that either the child will be found "normal" or that a specific cause will be determined and corrected. Some convince themselves that medical reports have been mixed-up, that names

were inadvertently switched on medical or school records, or that the tests were inaccurate. Even though they may partially know that the original diagnosis was correct, they continue to seek further evaluations in hopes that the first conclusion was indeed in error. The parents may perceive that something is wrong with the child but at present they are unable to recognize or admit to the child's problem. They find other explanations for his clumsiness, slowness, or lack of awareness.

Because it allows for an unconscious time to reorganize, the process of denial is often essential in maintaining sanity at this point in the parents' lives. It is not so much a closing of their eyes to the problem, but rather an inability to face the reality of the situation. "He can't be mentally retarded. He's just a baby. He seems so alert. IT'S JUST NOT POSSIBLE!"

A second feeling associated with the stage of Denial, is that of isolation. Parents of the newly diagnosed child often feel alone, singled out, and set apart. They feel certain that no one can experience their heartbreak. Parents often feel as though they are the only family with this problem, especially if there is no local support staff or group available. We must, however, be aware that the availability of such support staff and parent groups does not alone speed up the process of overcoming feelings of denial.

Fear, a third reaction, is generated by the unknown extent of the problem. What will it mean to both the immediate and extended family? How will this affect personal, family, and social desires? What will this mean in terms of added parental responsibility? And what will this mean for the child himself in terms of schooling, employment, social interactions, and a future life of independence?

During this first stage, other feelings often aroused are those of guilt and shame. Parents see the child as an extension of themselves. They feel, therefore, as though they have sinned or have done something so wrong that they are now being punished. Usually no specific act is discovered but any past wrong doing is seized and dwelt upon, making it the focus of the guilt reaction. It is often characterized by statements beginning "If only I'd ...", or, "If only I hadn't ...". It may be at this point that feelings of ambivalence (love and hate) surface toward the child, which result in compounding the emotional reactions.

Denial and it's accompanying emotions (isolation, fear, and guilt) are usually temporary and replaced by partial acceptance. As the parents begin to recuperate from this stage, their initial feelings of numbness begin to disappear and they begin to collect

themselves again. The response no longer is "No - it can't be happening to us", but, "Yes, this is it, there's no mistake."

When the act of denial is no longer purposeful, it is replaced by the second stage, Anger. Anger is often accompanied by feelings of rage, envy, and resentment. The logical questions at this point are: "Why me?, Why is this happening to us?, Why not someone else?"

At this point, parents may be angry at the child for deserting them, for cheating them out of opportunities, and for no longer gratifying their needs. Those previously mentioned ambivalent feelings toward the child may occur at this point. He may not only become the object of much love, but also of much hate for the severe deprivation of the earlier preconceived idea of their "perfect" child.

Expressions of anger and blame tend to be as rational as they are irrational. The parental reactions may result from the anticipation of the child's interference with the idealized future. They may also be a result of feelings inwardly directed for bringing this child into the world. Anger and blame are displaced in all directions. "The doctors are no good. The teacher is the problem. You don't understand." Parents blame their physician for the child's diagnosed medical condition. They blame the teacher for poor instruction if the child is

experiencing academic or learning problems. Anger is also displaced on those who can enjoy what they cannot. They are angry at families who do not have a handicapped child. Their feelings are accentuated in social and community settings when people talk of the accomplishments of their children in academic or extracurricular activities. Those conversations cut to the bone, and the main underlying thought at this point is "Why can't we have a normal family?" They are angry at themselves, at people, at family, or events suggesting normality, and at God, if they hold Him as a belief. Those persons outside of the immediate family function as emergency release valves for the parents - but not as a long lasting solution. It is a time when parents need to ventilate their rage and to be understood, not judged. At the same time, the family may withdraw from all social activities as they react to what they perceive from those outside the family as totally negative reactions to their child.

The third stage is Bargaining. We have all bargained and gained at one time or another. Now, in this tremendously catastrophic situation, parents may themselves petition for a grant based on a promise of good behavior. This is an attempt at postponing the inevitable. Most bargains are attempted in secret and with God. Examples may include more money to the church or a religious conversion in exchange for the grant. These promises

may be associated with quiet underlying guilt. "I haven't given enough money to the church or attended regularly. Jenny's final blood test is in three weeks. If you will only make the results negative, I promise to double or even triple my weekly donation to the church and leave the church half of my assets when I die."

When parents realize that the bargaining technique is not going to work to cure immediate conditions, they sink into Depression (the fourth stage of grief). Anger and rage are replaced by a sense of the great loss of what might have been. Depression is incurred not only for the loss of the preconceived perfect child and family unit but also for what may be denied lifelong to the child. During this stage, parents are allowed the time to accept that which cannot be changed.

Toward the end of this stage, parents begin to experience a void of feelings. The fight and struggle seem no longer necessary. They are neither depressed nor angry about their fate. Envy is no longer predominate. Parents begin to adapt to the situation and no longer feel the great pangs of anxiety. At this time parents begin to realize that things could be worse. They are entering into the last stage, that of Acceptance.

Acceptance has both emotional and intellectual levels. Parents must not only be able to verbalize intellectually an acceptance of themselves as parents and of their child and his

exceptionality, but they must also be able to emotionally promote the attitude of this total acceptance. "I know it is hard for Johnny to put on his shoes, but I'm letting him do it himself because he needs to accomplish this. It is well within his reach."

The stage of Acceptance in itself initiates the process of adjustment. Even though acceptance reaches a point of finality, adjustment is continual. It is faced by parents with each new life phase: age, physical development, social level expectations, and personal expectations. The stage of Acceptance and Adjustment does not imply that there are no longer prayers for a cure. It simply means that emotions have leveled off and that the parents can now face the reality of the situation and begin to make the best of it. The original "hope" of the misdiagnosis has now come full-circle to "hope" of establishing as normal of a situation for the family as possible and the taking of an active, positive part in pursuing that goal.

Let us not be so naive as to think that once emotions are played out that they are laid to rest. The changes which have occured in the emotional make-up are often permanent. We should also realize that because these stages are identified as a heirarchy they do not necessarily occur one after the other as in

the simple removal of each piece from a five block tower. They may overlap or even occur side byside. Not all parents are as deeply affected by emotional phases as others. Some take years to complete the grieving process while others may take a minimum amount of time. Still others may never complete the entire process. There may also be a re-occurance of any of the stages as the adjustment process unfolds. We are dealing with human emotions and reactions and although behavior can be somewhat predictable - individuality prevails.

As stated at the outset of this article, it is important for us as educators to become aware of the grieving process and how it relates to parents of the handicapped in their acceptance of the symbolic death of their child. Our role is not to counsel these parents. There are other professionals as well as support groups available for this purpose. Our responsibilities lie in the areas of awareness and understanding. As more and more children with handicaps are being identified, we must pursue an attitude of open-heartedness in not only acknowledging the stages of grief but also in allowing the parents to experience them. We must develop an attitude which is supportive and non-judgmental and one in which we can come to realize the individuality of each child, his parents, and their situation. Of primary concern should be the acceptance of parents as equal partners with us in

establishing the goals for the future. Finally, we must understand that the impending emotional stages are necessary for parents in order to heal themselves, to learn to cope, and to love and appreciate the special child who has been given to their care.

REFERENCE

Kubler-Ross, Elisabeth. On Death and Dying. New York: MacMillan Publishing Co., 1969.